

## Patient and Family Involvement

# Rating Recommendations for Consumers About Patient Safety: Sense, Common Sense, or Nonsense?

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Although there is little hard scientific evidence that patients and their families can help to prevent medical errors, several prominent health care organizations in the United States—including the National Patient Safety Foundation (NPSF), the U.S. Agency for Healthcare Research and Quality (AHRQ), The Joint Commission, and the Institute for Safe Medication Practices (ISMP)—have created print and online materials that encourage consumers to behave in ways that may improve patient safety.<sup>1-5</sup> These materials encourage patients to ask questions, read labels, and understand their medical conditions and care plans.

The notion that patients can help to prevent medical errors has face validity. Some patients are astute and motivated observers of care. Many can recognize lapses of care and bring these errors to the attention of their caregivers.<sup>6-9</sup> However, research studies about patient participation in patient safety are limited. Several investigators have surveyed patients about the value of a limited list of safety-oriented behaviors and actions and their willingness to use them.<sup>10-12</sup> In a survey of 2,078 patients, Waterman and colleagues found that 91% of respondents agreed that patients can help prevent medical errors. However, the respondents' willingness to take specific actions varied widely.

Eighty-five percent reported having asked questions about their care while hospitalized, but only 5% reported asking providers whether they had washed their hands. The authors found that patients who were very comfortable about error prevention were more likely to take action, and they recommend educational interventions to help patients become more engaged.<sup>12</sup> In a 2006 survey, the Kaiser Family Foundation found a slight increase compared with 2004 in the number of patients willing to take specific actions. For example, in 2006, 71% reported calling to check on test results, 54% brought a list of medications to a medical appointment, and 70% checked the medication they received from the pharmacist with the prescription the doctor wrote. However, the survey listed

## Article-at-a-Glance

**Background:** Although many organizations offer advice about the consumer's role in improving patient safety, little is known about these recommendations.

**Methods:** The Internet and medical literature were searched to identify patient safety recommendations for consumers. Recommendations were classified by type and tabulated by frequency. Nine investigators rated each recommendation for the quality of supporting empirical evidence, magnitude of benefit, and likely patient adherence. For a consumer perspective, 22 relatives of the investigators who were also mothers rated each recommendation.

**Results:** Twenty-six organizations identified 160 distinct recommendations; 115 (72%) addressed medication safety, 37 (23%) advised patients about preparation for hospitalization or surgery, and 18 (11%) offered general advice. Organizations most frequently advised patients to make a list of their medications (92% of organizations), to ask questions about their health and treatment (81%), to enlist an advocate (77%), and to learn about possible medication side effects (77%). Investigators assigned high scores to 11 of the 25 most frequently cited recommendations and to 4 of the 25 least common recommendations. There was little association between the frequency with which recommendations were promulgated and investigators' ratings ( $r = 0.27, p < .001$ ). Investigators' scores correlated with those of the mothers ( $r = 0.71, p < .001$ ).

**Discussion:** Contrary to expectation, there was little overlap among the 160 recommendations offered by the 26 organizations. Health care organizations offer many patient safety recommendations of limited value. These organizations should offer a concise and coherent set of recommendations on the basis of evidence, magnitude of benefit, and likely adherence.

only eight safety-related activities.<sup>11</sup> Other studies described the ability of some patients to identify adverse events and provided anecdotal reports of patient interventions to prevent harm in various settings.<sup>5,8-9,13-18</sup> Some authors questioned the value of the advice: Entwistle argued that some of the proposed patient activities may even be ineffective or counterproductive.<sup>19</sup>

To assess the scope and potential value of efforts to encourage consumer participation in preventing medical errors, we set out to characterize which measures, in fact, patients are advised to take. We sought to collect a list of consumer-oriented patient safety recommendations and to evaluate whether the advice was sound, informative, and actionable.<sup>20,21</sup> Because there is little scientific research about consumer engagement in patient safety, we hypothesized that organizations offering advice would have few and overlapping recommendations and that few consumers would find the recommendations valuable.

## Methods

### SELECTION OF RECOMMENDATIONS

To identify consumer-oriented patient safety interventions, from Fall 2005 through Spring 2006, we searched the medical literature via PubMed using the MeSH terms “patient participation” and “medical errors.” We examined 94 abstracts, hand-searched bibliographies of relevant papers, and then reviewed 34 articles. Although several articles included recommendations for consumers, none offered a comprehensive set or systematic evaluation. We then used the Internet to review the NPSF online-resources Web page, identifying 19 organizations that offered patient safety advice to consumers. We also used Google to search for the terms “patient information” and “patient safety.” This search yielded additional sources, including health plans; national chain pharmacies; and local, state, and national patient safety agencies and coalitions. In all, we identified three government agencies, five professional associations, four nonprofit groups, seven state and regional patient safety coalitions, five health plans, and two commercial entities in the United States that offered patient safety advice to consumers (Table 1, right). We collected all the brochures, fact sheets, Web pages, and written information attached to dispensed prescriptions offered by these organizations that we could find. We recognize that patients may receive safety advice from other sources, such as conversations with health practitioners, but restricted our analysis to material that we could document and that is widely accessible.

### CLASSIFICATION OF RECOMMENDATIONS

We developed a comprehensive list of patient safety recom-

**Table 1. Selected Organizations Offering Consumer-Oriented Patient Safety Recommendations**

	Abbreviation
<b>Government Agencies</b>	
U.S. Agency for Healthcare Research and Quality	AHRQ
U.S. Food and Drug Administration	FDA
Veterans Administration National Center for Patient Safety	NCPS
<b>Professional Associations</b>	
American Academy of Orthopaedic Surgeons	AAOS
Association of periOperative Registered Nurses	AORN
American Pharmacists Association	AphA
American Society of Health-System Pharmacists	ASHP
Center for Proper Medication Use (established by Pennsylvania Society of Health-System Pharmacists)	CPMU
<b>Nonprofit Agencies</b>	
Institute of Medicine	IOM
Institute for Safe Medication Practices	ISMP
The Joint Commission	TJC
National Patient Safety Foundation	NPSF
<b>State and Regional Coalitions</b>	
Hospital and Healthsystem Association of Pennsylvania	HAP
Madison Patient Safety Collaborative	MPSC
Maryland Patient Safety Center	MD
Massachusetts Coalition for the Prevention of Medical Errors	MCPME
National Council on Patient Information and Education	NCPIE
Ohio Patient Safety Institute	OPSI
Virginians Improving Patient Care and Safety	VIPC&S
<b>Health Plans and Pharmacies</b>	
Blue Cross Blue Shield (MA)	BCBS
Harvard Pilgrim Health Care (MA)	HPHC
Humana	
Kaiser Permanente	KP
Tufts Health Plan (MA)	THP
<b>Commercial</b>	
Expectation Management Medical Information (established by Rightfield Solutions, LLC)	EMMI
Consumer Health Information Corporation	CHIC

mendations for consumers by integrating all the consumer recommendations offered by the 26 organizations into a master list. Statements that included multiple concepts were disaggregated. For example, “Store your medicine in a dark, cool, dry place that’s safely away from children” was classified as “Store at the correct temperature and humidity” and “Keep medicine out of children’s reach.” Recommendations that were virtually identical in meaning despite small wording differences were classified as a single recommendation. Table 2 (page 208) provides examples of the classification method.

To assess the reliability of classification, a physician [S.N.W.], nurse [A.C.], and pharmacist [A.C.S.] investigator independently classified a random sample of 50 recommendations. Interrater reliability was satisfactory (kappa = 0.67,  $p < .001$ ).

**Table 2. Classification of Consumer Patient Safety Recommendations: Adjusting for Variation in Wording\***

Study Wording	Examples of Variations			
Educate yourself about your health conditions and your course of treatment.	The most important step for your protection is to educate yourself about your condition and treatment. (ISMP)	Find out all that you can about your illnesses and the medications you are taking. (APHA)	Seek information about illnesses or conditions that affect you and possible treatment options. (MPSC)	Learn about your condition and treatments by asking your doctor and nurse and by using other reliable sources. (AHRQ)
Make sure care providers verify your identity before any procedure or medication.	Do not let anyone give you medications without checking your hospital identification bracelet every time. (ISMP)	Make sure the doctor or nurse checks your wristband and asks your name before giving medicine. (TJC)	During a hospital stay, make sure everyone who tries to give you medication checks your hospital identification every time. (AAOS)	Do not be afraid to prompt your care team members to check your identifying information prior to administering any medications or performing procedures. (NPSF)
Take the drug for the full course of treatment.	Never stop taking medicine the doctor has told you to finish just because symptoms disappear. (FDA)	If you are taking an antibiotic to fight an infection, it is very important to take all of your medicine for as many days as your doctor prescribed, even if you feel better. (AHRQ)	To effectively manage your symptoms or disease, it's extremely important to take the medication for as long as your doctor recommends. (THP)	Take your medicine as it is prescribed and do not stop taking it without asking your doctor. (TJC)
Speak up when you don't understand or if something doesn't seem right.	If something doesn't seem right, call it to the attention of your doctor or health care professional. (NPSF)	Speak up if you have questions or concerns, and if you don't understand, ask again. (TJC)	Don't ever hesitate to ask questions, voice concerns, or speak up when you do not understand. (AAOS)	Insist on your concerns being addressed and your questions answered. (CPMU)
Ask the doctor to have the purpose of the drug printed on the prescription.	Encourage the prescribing professional to write the reason for the medication directly on the prescription. (ISMP)	Ask your doctor to write down on the prescription what the medicine is used for. (AHRQ)	When your doctor writes you a prescription, ask that the purpose for the medication be included and make sure you can read it. (VIPCS)	Tell your doctor you want the purpose for the medication written on the prescription. (APhA)
Turn on the lights so you don't accidentally take the wrong drug.	Using adequate light, read labels carefully before taking doses. (FDA)	Always turn on the light when giving or taking medicine. (ASHSP)	Do not take medicine in the dark. (HP)	Never take medications in the dark. (MCPME)
Enlist a relative or friend to act as advocate, especially if you are under stress or are not feeling well.	Ask a family member or friend to be with you in the hospital or medical facility. (TJC)	If you're not able to observe or participate fully in your care, ask a family member or friend to assist. (NPSF)	Bring someone with you as a second pair of eyes and ears. (AAOS)	Ask a family member or friend to be there with you and to be your advocate (someone who can help get things done and speak up for you if you can't). (AHRQ)
Never share medicine with another person.	Never give your prescription medicine to somebody else or take prescription medicine that wasn't prescribed for you. (AHRQ)	Never take another person's medicine. (FDA)	Never share your medications with others or take another person's medications. (OPSI)	Never give your medication to anyone else. (CPMU)
Make a list of all medications you are taking. Include dosage and over-the-counter, herbal supplements, vitamins.	Make a list of everything you take, how much, and how often you take it. (EMMI)	Share with your doctor a list of your current medicines, vitamins, herbs, and supplements. (TJC)	Keep a record of all the over-the-counter medicines, prescription medicines, dietary supplements, and herbal remedies you take. (NCPIE)	Keep a record of all your current medicines, including their names and regimens. (FDA)
Check expiration dates periodically.	Check your medicines (prescription and over-the-counter) every 6 months for their expiration date and get rid of all drugs that are out of date. (ISMP)	Throw away all products that are outdated or have not been used in awhile. (OPSI)	Dispose of all medicines promptly after their expiration date. (NCPIE)	Check the expiration date on all medications. (MCPME)
When you pick up the drug at the pharmacy, check to make sure it is the correct medication.	Always check your prescriptions before you leave the store to make sure the medication is for you and is labeled clearly. (OPSI)	Before you leave the pharmacy, open the bag and double-check the medication to make sure you've received the correct product. (MCPME)	When you pick up your medicine from the pharmacy, ask: Is this the medicine that my doctor prescribed? (AHRQ)	Double-check that you have the correct medication when you pick up your prescription at the pharmacy. (AAOS)

\* Organization abbreviations are spelled out in Table 1.

## GRADING PATIENT SAFETY RECOMMENDATIONS

The authors, an interdisciplinary group of nine clinicians and patient safety researchers, graded each recommendation using three criteria:

1. The quality of the empirical evidence supporting the recommendation
2. The likely magnitude of benefit in preventing medical errors and adverse events
3. The likelihood of consumer adherence

Participants scored each recommendation independently using a three-point scale (1 = low, 2 = moderate, 3 = high). The evidence was rated as high quality if it was based on research studies; moderate quality if it was based on anecdotal reports or plausibility; and low quality if it had little or no empirical support. The magnitude of benefit was rated high if the recommendations would protect some individuals from serious harm or offer some protection to many; moderate benefit if it protected a few patients from harm; and low benefit if it had little or no impact on patient safety, or was so widely known that the recommendation was judged trivial or obvious. The likelihood of adherence was rated according to whether the respondent thought that people are highly likely to follow this recommendation (high probability of adherence), some people will follow it (moderate) or few people will follow it (low). Without a priori knowledge of the relative contribution of each criterion to the overall value of the recommendation, we assigned a composite score to each recommendation by calculating the unweighted mean of the three components.

To compare investigators' scores with a reference group, we recruited first- and second-degree female relatives of the study team (grandmothers, mothers, sisters, daughters, aunts, and nieces, as well as in-laws) who were also mothers. We reasoned that the good judgment, wisdom, and practical experience traditionally ascribed to motherhood could provide a practical assessment of the potential impact of the recommendations and consumer adherence.

We collected mothers' contact information from members of the study team, and a single member of the team contacted each by e-mail or mail to invite them to participate. Potential respondents were assured of their anonymity. We excluded mothers with health care careers. Of 29 invited relatives, 22 (76%) returned completed surveys. We asked mothers to assess the benefit of and likely adherence to each recommendation but did not ask them to rate the empirical basis for the recommendation as we thought it unlikely that they were familiar with the research literature. We acknowledge that this convenience sample is liable to charges of bias and sexism, but we

contend that it provided the requisite nontechnical consumer judgments.

## DATA ANALYSES

Analyses were descriptive. We tabulated the number and types of recommendations offered by organizations. We hypothesized that recommendations offered by diverse organizations would converge because consumer information was readily available. Further, we hypothesized that some organizations' missions and constituencies would lead to a concentration of recommendations in a narrow domain. For example, pharmacist-based organizations were expected to emphasize safe prescribing, dispensing, and administration rather than perioperative management.

To examine the value of consumer-oriented patient safety recommendations, we calculated the arithmetic mean score for each recommendation by investigators and mothers and ranked the recommendations ordinally by rating (range, 1.0–3.0). We examined whether the recommendations offered most and least frequently were rated favorably (or unfavorably) by each respondent group. We defined very high ratings as a mean score of  $\geq 2.5$  and very low ratings as a mean score of  $\leq 1.5$ . We hypothesized that investigators and mothers would identify a common set of high- and low-rated recommendations. We used Spearman's rank correlation to examine the association between investigators' and mothers' overall ratings and their ratings of component scores for quality of evidence, health benefit, and adherence. We used Student's t-test to compare overall and composite scores within and across groups. We also used Spearman's correlation to examine the association between overall ratings and the number of health care organizations that promulgated the recommendation. Statistical analyses used Stata 9.1 (StataCorp, College Station, Texas). The Dana-Farber Harvard Cancer Center Institutional Review Board approved the study in advance.

## Results

### NUMBER AND TYPE OF RECOMMENDATIONS

We identified a total of 160 distinct patient safety recommendations for consumers. Eighteen (11%) offered general advice for patients, including advice about educating oneself about one's care and condition, the importance of vigilance and effective communication, and the value of participatory decision making. One-hundred fifteen (72%) addressed medication safety and the safe use of medications before hospitalization or surgery. Patients were advised to carry up-to-date medication lists, ask medication-related questions, follow instructions,



keep children safe, and store medications appropriately. Another 37 (23%) advised patients how to prepare for a hospitalization or upcoming surgery (including 10 recommendations that also addressed medication safety). Appendix 1 (available in the online article) lists a complete set of recommendations.

### **MOST AND LEAST COMMON RECOMMENDATIONS**

The 25 highest and lowest frequency recommendations are shown in Table 3 (page 211). The most common recommendation—"Make a list of all medications you are taking. Include dosage and over-the-counter drugs, herbal supplements, vitamins"—was offered by 24 (92%) of the 26 organizations. Four recommendations were shared by 20 (77%) organizations, and 28 (18%) recommendations by half of the organizations. Conversely, 86 (54%) recommendations were offered by five or fewer organizations, and 20 (13%) were advanced by a single organization.

### **RECOMMENDATION BY SOURCE**

Table 4 (page 213) summarizes the number and type of recommendation offered by each organization. On average, each organization offered 40 recommendations (range 12–61). All the organizations offered at least one medication-related recommendation, 24 had at least one general safety recommendation, and 19 had at least one recommendation related to hospitalization or surgery. As expected, organizations that focused on medication safety, such as the National Council on Patient Information and Education, ISMP, and the U.S. Food and Drug Administration, generally offered the largest number of medication-related recommendations. Similarly, the American Academy of Orthopaedic Surgeons (AAOS) and the Joint Commission offered the most recommendations related to hospitalization and surgery.

### **INVESTIGATORS' ASSESSMENTS**

We created a ranked list of recommendations based on investigator ratings and present the highest and lowest-rated recommendations in Table 5 (page 214). The mean composite score was 2.27 (standard deviation [S.D.], 0.31; range, 1.37–2.93). Investigators rated the potential benefit of recommendations (mean, 2.52; S.D., 0.35) higher than either the quality of evidence (mean, 2.29; S.D., 0.34) or likely adherence (mean, 2.01; S.D., 0.40;  $p < .001$  for all comparisons).

Investigators' ratings correlated weakly with the frequency with which recommendations were promulgated ( $r = 0.27$ ,  $p < .001$ ). Investigators rated 44 (28%) recommendations with a high score ( $\geq 2.5$ ). They rated only one recommendation unfavorably

( $\leq 1.5$ ): "Read any written material, such as leaflets or inserts." Investigators gave high scores to 11 of the 25 most frequently cited recommendations, a low score to one of the 25, and intermediate scores to the remainder. In contrast, they assigned high scores to 4 of the 25 least frequently cited recommendations.

### **MOTHERS' ASSESSMENTS**

Mothers were somewhat less critical than investigators, with a mean composite score of 2.36 (S.D., 0.29; range 1.58–3.00). For direct comparison, investigators' composite rating of benefit and adherence was 2.27 (S.D., 0.33; range, 1.33–2.89). Like the investigators, they rated the potential benefit of recommendations (mean, 2.64; S.D., 0.24) higher than likely adherence (mean, 2.08; S.D., 0.39;  $p < .001$  for all comparisons). Mothers' scores exceeded that of the corresponding investigators' rating by a small but statistically significant amount ( $p < .001$  for all comparisons, Figure 1, page 212).

Like investigators' ratings, mothers' ratings correlated weakly with the frequency with which recommendations were promulgated ( $r = 0.16$ ;  $p = .04$ ). Mothers gave high scores to 61 (38%) recommendations, including 13 of the 25 most frequently cited recommendations. There were no unfavorable ratings. In contrast, eight of the mothers' highly rated items were among the 25 least frequently cited recommendations.

Mothers' and investigators' scores correlated well ( $r = 0.71$ ;  $p < .001$ ). Mothers assigned high scores to 35 (80%) of investigators' 44 highest-rated recommendations.

## **Discussion**

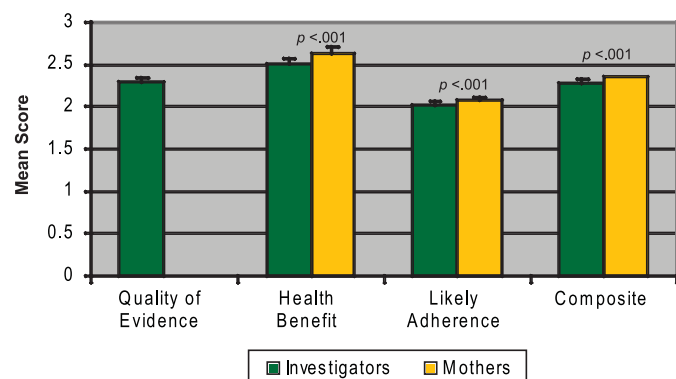
In this study of patient safety recommendations for consumers, we identified 160 distinct recommendations offered by 26 health care organizations in the United States. Contrary to our expectation, there was little overlap among the recommendations offered by different organizations. In addition, we found little relationship between the frequency with which recommendations were proffered and the assessment of their value by either investigators or consumers. Investigators assigned a highly favorable score to only 11 of the 25 most frequently cited recommendations, while the mothers gave high scores to only 13 of these common recommendations.

What can we conclude from these findings? First, consumers encounter a wide array of patient safety recommendations. The number of recommendations from multiple sources may dilute the impact of the message that their sponsors intended. Second, there are only weak relationships between the value of recommendations and their frequency, further eroding the impact. In

**Table 3. Most and Least Common Recommendations Among 26 Health Care Organizations**

	Organizations with the Recommendation	
	Number	Percent
<b>Most Common 25</b>		
Make a list of all medications you are taking. Include dosage and over-the-counter, herbal supplements, vitamins. (Recommendation number 7.1)	24	92
Ask questions about your health, your treatment, and your drugs. Don't be embarrassed to keep asking until you understand. (1.2)	21	81
Enlist a relative or friend to act as advocate, especially if you are under stress or are not feeling well. (4.2)	20	77
What are the possible side effects, and what should I do if I have them? (8.8)	20	77
What is it for? Why am I taking it? (8.1)	19	73
Educate yourself about your health conditions and your course of treatment. (1.1)	18	69
What are the brand and generic names? (8.2)	17	65
Does it interact with any foods, alcohol, or other medications I take? (8.12)	17	65
Read any written material, such as leaflets or inserts. (10.5)	17	65
Speak up when you don't understand or if something doesn't seem right. (3.2)	16	62
List medication and food allergies. (7.2)	16	62
How should I take it? (8.5)	16	62
When should I take it? (8.6)	16	62
Follow the doctor or pharmacist's instructions. (10.1)	16	62
How long should I take it? (8.7)	15	58
Report unexpected symptoms or reactions to your doctor or pharmacist. (11.1)	15	58
Show it to every doctor who treats you. (7.4)	14	54
What should I do if I miss a dose? (8.10)	14	54
Try to use the same pharmacy all the time so your records are in one place. (15.1)	14	54
Write down answers to your questions. (1.4)	13	50
Never share medicine with another person. (9.7)	13	50
Read the label every time you take a dose to make sure you have the right drug. (10.8)	13	50
When you pick up the drug at the pharmacy, check to make sure it is the correct medication. (15.3)	13	50
Include information about serious health conditions and medical history. (7.3)	12	46
Don't discontinue or change dosage without talking with your doctor. (10.7)	12	46
<b>Least Common 25</b>		
Ask who will manage your care while you are in the hospital. (18.12)	2	8
Verify the information on your identification bracelet. (18.16)	2	8
Ask how long intravenous administration should take. Observe to see if it is running too fast or slow. (19.8)	2	8
Tell your nurse or doctor if you don't feel well after receiving medication, or if you think you are having side effects. (19.9)	2	8
Let your nurse know if you notice any problems with dressings or catheters. (20.7)	2	8
Don't let yourself be pressured by a doctor, pharmacist, advertisement, or anyone else, into taking any drug. Ask if there are non-drug treatments for your symptoms. (9.5)	1	4
Don't pressure your doctor into prescribing drugs for you. (9.6)	1	4
Don't keep secrets from your doctor (e.g., if you stop taking a drug the doctor prescribed, or you use other drugs or alcohol that might interact). (11.7)	1	4
Don't mix drugs in containers with others. (12.3)	1	4
Take only the recommended amount at the recommended intervals stated on the label. (13.5)	1	4
Ask the pharmacist how soon you should expect results. (13.9)	1	4
Learn to recognize liquid medication by smell. (15.4)	1	4
When using a dosing syringe with a cap, discard the cap before use. (16.4)	1	4
Never use medicine for use other than mentioned on the label, unless directed by a doctor. (16.8)	1	4
Never try to remember a dose from a previous illness; read the label each time. (16.9)	1	4
Avoid taking medication in the presence of children, as they may imitate. (16.13)	1	4
If you need to use a syringe, bring a copy of your prescription so you can get through security. (17.2)	1	4
Bring a copy of your written prescription in case you run out. (17.3)	1	4
Ask pharmacist about adjusting timing of doses when changing time zones. (17.5)	1	4
Visit the hospital's web site to learn what you need to know before you are admitted. (18.8)	1	4
Keep records from previous hospitalizations; share them with your health care team. (18.15)	1	4
Ask for a copy of your hospital medication administration record. Check it for accuracy. (19.3)	1	4
Read the contents of the intravenous bag. (19.7)	1	4
Make sure you are familiar with the operation of any equipment used in your care. (20.5)	1	4
Follow instructions about breathing treatments and getting out of bed. (21.1)	1	4

## Comparison of Investigators' and Mothers' Ratings of Patient Safety Recommendations



**Figure 1.** There was a small but statistically significant difference between investigators' and mothers' mean ratings of the health benefit and consumers' likely adherence to patient safety recommendations. Overall, investigators' and mothers' composite ratings were moderately high (2.27 and 2.36, respectively, on a scale from 0 to 3). Note that the composite score is the unweighted mean score of each component.

fact, some recommendations are well known to the public. In a consumer survey sponsored by the Kaiser Family Foundation and AHRQ, 83% of respondents indicated that they had used one of eight safety practices in the past year, such as asking the doctor questions about their health or treatment, calling to check on test results, and checking the medication dispensed at the pharmacy against the doctor's prescription.<sup>11</sup>

In addition, organizations should consider the likelihood of adherence. In a study by Hibbard and colleagues, investigators asked 195 patients to evaluate a set of 14 recommendations for preventing medical errors.<sup>10</sup> Patients perceived that many recommendations were potentially effective, such as choosing an experienced surgeon or making sure that doctors know all of one's prescription medications and drug allergies. However, many patients said that they were unlikely to follow the recommendations. Similarly, in Entwistle and colleagues' analysis of five consumer-oriented patient safety advisories, the authors worried about the difficulty of implementing recommendations that require patients to challenge professionals' behaviors, and about inappropriately shifting responsibility for patient safety from clinicians onto patients.<sup>21</sup> Clearly, consumers' willingness and ability to follow advice should inform the selection of recommendations.

On the basis of our investigation, a limited number of consumer recommendations may provide the greatest potential for improvement. Some high-value recommendations advise consumers about how to respond to adverse drug events, such as an

accidental poisoning or anaphylaxis. Others offer precautionary measures to prevent harm from medications (for example, maintain an up-to-date drug list) or surgery (for example, ensure that your identity is verified and the surgical site is marked). Such recommendations are likely to be acceptable to patients while offering information that allows them to improve their own care. The following are five recommendations that are most acceptable and most likely to be followed:

1. If you think you have taken an overdose or a child has taken medication by accident call your local poison control center or your health care provider at once.
2. If you develop itching or swelling or have trouble breathing after taking a new medicine, get medical help immediately.
3. Make sure care providers verify your identity before any procedure or medication.
4. Ask about risks and potential complications of surgery, expected outcomes, and alternatives to surgery.
5. Review your medications with doctor, nurse, or pharmacist before you go home from the hospital. Change your medication list accordingly.

This study has several limitations. Although we attempted to identify all available sources of consumer patient safety recommendations, we may have inadvertently omitted some influential organizations. The variety of types of organizations in our sample, however, contributes to the face validity of our results. Second, we collected and analyzed recommendations in 2005-2006. Because organizations produce and retire consumer materials regularly, some recommendations may have evolved since we undertook this project. Third, it was not possible to estimate the degree to which consumers were exposed to various messages. Therefore, our description of the prevalence of various recommendations may not accurately reflect the distribution or impact of the message on the public. Fourth, consumers are a heterogeneous population. Some groups may have greater health literacy or access than others. As a result, certain recommendations may be of higher value among specific subpopulations than among others. Clearly, messages must be targeted to the audience. Fifth, ratings of recommendations reflect subjective judgments of investigators and mothers. Although we took measures to ensure the independence and anonymity of mothers' responses, it is possible that the correlation of mothers' responses with investigators' reflects shared attitudes, experiences, and similar socioeconomic status.

Consumers face a wide array of patient safety recommendations offered in good faith by well-meaning and reputable organizations. Unfortunately, there appear to be too many recommendations to be practical, and some are of dubious value.

Table 4. Number and Type of Recommendations by Organization\*

	General Health Care Safety						Medication Safety										Hospital and Surgery					
	Education	Infection Control	Vigilance	Communication	Care Coordination	Patient Participation	Medical Lists and Information	Rx Questions	Rx Precautions	Instructions	Communication	Storage	Over-the-Counter	Tampering	Pharmacy	Children	Travel	Before Hospitalization	Medication	Precautions	Instructions	TOTAL
No. of recommendations in each category	4	3	2	5	1	3	12	17	8	11	10	9	9	2	7	14	6	17	10	8	2	160
AHRQ	4	1	1	4	1	3	6	14	3	5	1	0	0	0	3	0	0	11	1	2	1	61
FDA	3	0	0	1	0	0	5	9	2	7	4	3	2	2	1	10	0	0	1	2	0	52
NCPS	2	2	2	3	0	1	2	0	0	0	1	0	0	0	1	0	0	7	0	0	0	21
AAOS	4	2	1	5	0	3	4	0	1	3	1	0	0	0	1	1	0	11	3	4	1	45
AORN	2	0	1	1	0	2	2	0	2	5	2	3	0	0	3	1	0	11	0	1	1	37
Apha	4	0	1	0	0	0	5	15	3	1	0	4	4	0	1	2	0	0	4	3	0	47
ASHSP	0	0	1	1	0	0	2	5	0	4	3	4	0	2	2	3	5	0	0	0	0	32
CMPU	3	0	1	1	0	0	4	9	4	6	5	4	3	2	4	3	3	1	3	0	0	56
IOM	0	0	0	1	0	0	3	7	1	1	0	0	0	0	2	0	0	0	3	0	0	18
ISMP	2	0	2	1	0	0	6	12	4	7	4	8	0	0	2	3	0	2	6	2	0	61
TJC	4	2	1	1	0	3	5	10	4	6	1	0	0	0	1	0	0	7	7	4	1	57
NPSF	3	2	2	3	0	3	7	13	0	5	2	3	0	0	4	2	0	4	0	5	2	60
HAP	3	0	1	1	0	0	2	5	0	0	0	0	0	0	0	0	0	1	0	0	1	14
MPSC	3	0	1	2	0	0	6	8	4	8	2	7	3	0	4	2	0	0	6	2	0	58
MD	3	1	2	2	0	0	2	3	2	1	0	0	0	0	0	0	0	5	0	1	1	23
MCPME	1	0	0	0	0	0	6	8	2	7	2	4	0	0	3	1	0	0	3	0	0	37
NCPIE	3	0	0	0	1	0	3	16	2	6	3	3	9	0	1	7	0	0	0	0	0	54
OPSI	2	0	0	0	1	0	4	13	2	2	3	2	0	0	3	1	0	0	0	0	0	33
VIPC&S	2	1	1	2	0	0	5	10	3	2	0	1	0	0	3	0	0	3	3	5	1	42
BCBS	0	0	0	0	0	0	2	0	1	1	0	5	1	0	1	1	0	0	0	0	0	12
HP	0	0	0	0	0	0	3	15	1	5	4	2	6	0	1	2	0	0	0	0	0	39
HUMANA	3	0	2	2	0	1	7	5	1	2	2	1	0	0	1	0	0	8	0	0	0	35
KP	4	1	2	4	1	2	4	6	1	3	0	0	0	0	3	0	0	6	0	1	1	39
THP	4	0	0	3	0	1	9	12	0	6	3	2	3	0	4	0	2	0	0	0	0	49
CHIC	1	0	0	1	0	0	1	11	1	5	4	2	0	0	3	0	0	0	0	0	0	29
EMMI	2	2	0	1	0	0	4	4	1	3	2	2	0	0	2	1	0	2	2	5	1	34
Total	62	14	22	40	4	19	109	210	45	101	49	60	31	6	54	40	10	79	42	37	11	
Possible	104	78	52	130	26	78	312	442	208	286	260	234	234	52	182	364	156	442	260	208	52	
Total/Possible	59.6	17.9	42.3	30.8	15.4	24.4	34.9	47.5	21.6	35.3	18.8	25.6	13.2	11.5	29.7	11.0	6.4	17.9	16.2	17.8	21.2	

\* Organization abbreviations are spelled out in Table 1. Rx, prescription.

Even the *Five Steps to Safer Health Care* “short list” of recommendations offered by AHRQ, for example, contains 20 distinct statements. Some consumer recommendations represent an obvious bromide, while others offer advice with little prospect of adherence or minimal benefit. Research is needed to identify the recommendations with the greatest likelihood of improving patient safety. Until then, health care organizations should encourage consumer engagement by offering patients as concise and coherent a set of recommendations as possible on the basis of the face validity and empirical evidence for the recommendations, the magnitude of benefit, and the likelihood of adherence. **J**

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**Table 5. Investigators' Highest and Lowest Rated Recommendations**

<b>Top 25</b>	<b>Rank</b>
If you think you have taken an overdose or a child has taken medication by accident call your local poison control center or your health care provider at once. (11.3)	1
If you develop itching or swelling or have trouble breathing after taking a new medicine, get medical help immediately. (11.2)	2
Make sure care providers verify your identity before any procedure or medication. (20.1)	3
Ask about risks and potential complications of surgery, expected outcomes, and alternatives to surgery. (18.3)	4
Review your medications with doctor, nurse, or pharmacist before you go home. Change medication list accordingly. (19.10)	5
Report unexpected symptoms or reactions to your doctor or pharmacist. (11.1)	6
Wear a MedAlert bracelet if you have severe drug or food allergies. (11.10)	6
Use child-resistant caps. (16.2)	6
Make sure the correct site is marked. (20.4)	6
Make a list of all medications you are taking. Include dosage and over-the-counter, herbal supplements, vitamins. (7.1)	6
List medication and food allergies. (7.2)	6
Keep medicine out of children's reach. (16.1)	6
Ask if you can take your regular medications, and what to eat or drink. (18.2)	6
Tell your doctor if you smoke or use alcohol. (11.6)	14
Verify the information on your identification bracelet. (18.16)	14
Wash your hands. (2.1)	14
Tell your nurse or doctor if you don't feel well after receiving medication, or if you think you are having side effects (19.9)	14
Make sure the dose is appropriate for the child's weight and age. (16.6)	18
Remind care providers of allergies before any procedure. (20.2)	18
What are the possible side effects, and what should I do if I have them? (8.8)	18
How much should I take? (8.4)	21
Follow the doctor or pharmacist's instructions. (10.1)	21
When you pick up the drug at the pharmacy, check to make sure it is the correct medication. (15.3)	21
Give the child all of the medicine prescribed, even if he/she is feeling better. (16.11)	21
What is it for? Why am I taking it? (8.1)	25
<b>Bottom 25</b>	<b>Rank</b>
Keep in original containers. (12.2)	136
Buy drugs that treat only the symptoms you have. Don't buy a multi-symptom preparation unless you have all the symptoms. (13.4)	136
Check expiration dates periodically. (12.8)	138
How soon should I expect results? (8.15)	139
Ask pharmacist about adjusting timing of doses when changing time zones. (17.5)	139
Keep a "medicine diary" of medication experiences to show doctor or pharmacist, so they can decide if you have had side effects. (7.10)	141
What does it look like? (8.3)	141
Don't let yourself be pressured by a doctor, pharmacist, advertisement, or anyone else, into taking any drug. Ask if there are non-drug treatments for your symptoms. (9.5)	141
Be aware of the risks of ordering drugs online. (15.7)	141
Bring a copy of your written prescription in case you run out. (17.3)	141
How will I know it is working? (8.13)	141
Will I need tests to know if the drug is working? (8.14)	147
Ask how you should store the medication. (12.1)	147
Don't mix drugs in containers with others. (12.3)	147
Ask for a copy of your hospital medication administration record. Check it for accuracy. (19.3)	147
Learn to recognize liquid medication by smell. (15.4)	151
When using a dosing syringe with a cap, discard the cap before use. (16.4)	151
Discard outdated medications carefully. (12.9)	153
Give a copy of your list to a friend or relative. (7.5)	154
Avoid taking medication in the presence of children, as they may imitate. (16.13)	155
Ask the pharmacist how long it is safe to take the medicine. (13.8)	156
Visit the hospital's web site to learn what you need to know before you are admitted. (18.8)	157
Select your pharmacist carefully. (15.2)	158
Make sure you are familiar with the operation of any equipment used in your care. (20.5)	158
Ask the pharmacist how soon you should expect results. (13.9)	160

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### Online-Only Content

See the online version of this article for Appendix 1. Patient Safety Recommendations for Consumers.

## Appendix 1. Patient Safety Recommendations for Consumers

### General Health Care Safety

1. Education
  - 1.1. Educate yourself about your health conditions and your course of treatment.
  - 1.2. Ask questions about your health, your treatment, and your drugs. Don't be embarrassed to keep asking until you understand.
  - 1.3. Write your questions ahead of time.
  - 1.4. Write down answers to your questions.
2. Infection control
  - 2.1. Wash your hands.
  - 2.2. Remind caregivers to wash their hands.
  - 2.3. Remind visitors to wash their hands.
3. Vigilance
  - 3.1 Pay attention to your care.
  - 3.2. Speak up when you don't understand or if something doesn't seem right.
4. Communication
  - 4.1. Be honest and complete when you talk with your doctor.
  - 4.2. Enlist a relative or friend to act as advocate, especially if you are under stress or are not feeling well.
  - 4.3. Report anything unusual to your doctor.
  - 4.4. Receive all instructions in writing and verbally. Make sure you understand them.
  - 4.5. If you have a test, ask about results. Don't assume no news is good news.
5. Care coordination
  - 5.1. Make sure one doctor is in charge of your care.
6. Patient participation
  - 6.1. Participate in decisions about your care. Make sure you and your doctor agree about each step of your care.
  - 6.2. Consider getting a second opinion if you are unsure your doctors' plan is right for you.
  - 6.3. Evaluate the hospital or clinic where you will receive care, to make certain it is the right one for your needs.

### Medication Safety

7. Medication lists and information
  - 7.1. Make a list of all medications you are taking. Include dosage and over-the-counter, herbal supplements, vitamins.
  - 7.2. List medication and food allergies.
  - 7.3. Include information about serious health conditions and medical history.
  - 7.4. Show it to every doctor who treats you.
  - 7.5. Give a copy of your list to a friend or relative.
  - 7.6. Bring it with you when you go to the hospital.
  - 7.7. Make sure the pharmacist knows every drug you take.
  - 7.8. Tell the pharmacist about allergies and herbal remedies.
  - 7.9. Have phone numbers of health care providers, pharmacists, emergency medical service, and poison control readily available.
  - 7.10. Keep a "medicine diary" of medication experiences to show doctor or pharmacist, so they can decide if you have had side effects.
  - 7.11. Have periodic "brown bag" checks with your doctor or pharmacist.
  - 7.12. Ask your doctor periodically to review long-term treatments.
8. Prescription questions
  - 8.1. What is it for? Why am I taking it?
  - 8.2. What are the brand and generic names?
  - 8.3. What does it look like?
  - 8.4. How much should I take?
  - 8.5. How should I take it?
  - 8.6. When should I take it?
  - 8.7. How long should I take it?
  - 8.8. What are the possible side effects, and what should I do if I have them?
  - 8.9. What can I do to avoid or manage the possible side effects?
  - 8.10. What should I do if I miss a dose?
  - 8.11. Does it replace something I am taking now?
  - 8.12. Does it interact with any foods, alcohol, or other medications I take?
  - 8.13. How will I know it is working?
  - 8.14. Will I need tests to know if the drug is working?

- 8.15. How soon should I expect results?
- 8.16. Should I avoid any activities?
- 8.17. Is it safe to become pregnant or breastfeed while taking this medicine?
9. Prescription precautions
  - 9.1. Make sure you can read the physician's writing on the prescription.
  - 9.2. Ask the doctor to have the purpose of the drug printed on the prescription.
  - 9.3. If your doctor gives you samples, ask if they might interact with your other medications.
  - 9.4. Remind the doctor of any allergies or drug reactions when you get a new prescription.
  - 9.5. Don't let yourself be pressured by a doctor, pharmacist, advertisement, or anyone else, into taking any drug. Ask if there are non-drug treatments for your symptoms.
  - 9.6. Don't pressure your doctor into prescribing drugs for you.
  - 9.7. Never share medicine with another person.
  - 9.8. Learn as much as you can about your medicines.
10. Instructions
  - 10.1. Follow the doctor or pharmacist's instructions.
  - 10.2. Show you understand by repeating information back to the doctor or pharmacist.
  - 10.3. Tell your doctor how you actually take your medicine, especially if this is different from the original directions.
  - 10.4. Tell your doctor about anything that could affect your ability to take medicine, such as difficulty swallowing or forgetting to take it.
  - 10.5. Read any written material, such as leaflets or inserts.
  - 10.6. Take the drug for the full course of treatment.
  - 10.7. Don't discontinue or change dosage without talking with your doctor.
  - 10.8. Read the label every time you take a dose to make sure you have the right drug.
  - 10.9. Turn on the lights so you don't accidentally take the wrong drug.
  - 10.10. Don't crush, break, or chew tablets or capsules unless instructed.
  - 10.11. Use only the cup or measuring device that came with liquid medications.
11. Communication
  - 11.1. Report unexpected symptoms or reactions to your doctor or pharmacist.
  - 11.2. If you develop itching or swelling or have trouble breathing after taking a new medicine, get medical help immediately.
  - 11.3. If you think you have taken an overdose or a child has taken medication by accident call your local poison control center or your health care provider at once.
  - 11.4. Tell your doctor about reactions you have had to drugs in the past.
  - 11.5. Tell your doctor if you follow a special diet or take supplements.
  - 11.6. Tell your doctor if you smoke or use alcohol.
  - 11.7. Don't keep secrets from your doctor (e.g., if you stop taking a drug the doctor prescribed, or you use other drugs or alcohol that might interact).
  - 11.8. Tell your doctor if you have trouble remembering to take your medicine, so he/she won't think the medicine isn't working and might prescribe another drug.
  - 11.9. Find out how far ahead you need to order refills, so you don't disrupt your medication regimen.
  - 11.10. Wear a MedAlert bracelet if you have severe drug or food allergies.
12. Storage
  - 12.1. Ask how you should store the medication.
  - 12.2. Keep in original containers.
  - 12.3. Don't mix drugs in containers with others.
  - 12.4. Store at the correct temperature and humidity.
  - 12.5. Keep people medicine separate from pet medicine.
  - 12.6. Keep medicine apart from dangerous substances, e.g., household chemicals
  - 12.7. Don't keep tubes of medicine near toothpaste.
  - 12.8. Check expiration dates periodically.
  - 12.9. Discard outdated medications carefully.

## Appendix 1. Patient Safety Recommendations for Consumers (continued)

### 13. Over-the-counter

- 13.1. Read labels of over-the-counter drugs to make sure they don't interact with something else you are taking or contain something to which you are allergic.
- 13.2. Ask the pharmacist or doctor before using the first time if you have questions.
- 13.3. Ask if the medicine could affect your medical conditions.
- 13.4. Buy drugs that treat only the symptoms you have. Don't buy a multi-symptom preparation unless you have all the symptoms.
- 13.5. Take only the recommended amount at the recommended intervals stated on the label.
- 13.6. Don't combine over-the-counter and prescription drugs without consulting your doctor or pharmacist.
- 13.7. Ask the pharmacist about possible side effects.
- 13.8. Ask the pharmacist how long it is safe to take the medicine.
- 13.9. Ask the pharmacist how soon you should expect results.

### 14. Tampering

- 14.1. Look at the packaging for signs of tampering.
- 14.2. Look at the medicine. Never take medicine that is discolored, has an unusual odor, or seems suspicious in some other way. Return it to pharmacy.

### 15. Pharmacy

- 15.1. Try to use the same pharmacy all the time so your records are in one place.
- 15.2. Select your pharmacist carefully.
- 15.3. When you pick up the drug at the pharmacy, check to make sure it is the correct medication.
- 15.4. Learn to recognize liquid medication by smell.
- 15.5. When you pick up the drug, consult with the pharmacist to confirm your understanding of the information you got from the doctor.
- 15.6. When you get a refill, look at the medicine—does it look the same as what you have been taking? If not, ask the pharmacist.
- 15.7. Be aware of the risks of ordering drugs online.

### 16. Children

- 16.1. Keep medicine out of children's reach.
- 16.2. Use child-resistant caps.
- 16.3. Use dose caps carefully.
- 16.4. When using a dosing syringe with a cap, discard the cap before use.
- 16.5. Never guess when converting measurements.
- 16.6. Make sure the dose is appropriate for the child's weight and age.
- 16.7. Check with the doctor or pharmacist before giving a child more than one medicine.
- 16.8. Never use medicine for use other than mentioned on the label, unless directed by a doctor.
- 16.9. Never try to remember a dose from a previous illness; read the label each time.
- 16.10. Don't give aspirin to children unless a doctor has prescribed it.
- 16.11. Give the child all of the medicine prescribed, even if he or she is feeling better.
- 16.12. Never give adult medicine to a child unless it is recommended on the label or by a doctor.
- 16.13. Avoid taking medication in the presence of children, as they may imitate.
- 16.14. Don't call medicine "candy."

### 17. Travel

- 17.1. Keep medications in carry-on luggage.
- 17.2. If you need to use a syringe, bring a copy of your prescription so you can get through security.
- 17.3. Bring a copy of your written prescription in case you run out.
- 17.4. Carry prescriber's and pharmacist's phone numbers.
- 17.5. Ask pharmacist about adjusting timing of doses when changing time zones.
- 17.6. Bring extra medication in case your travel is delayed.

### Preparing for Hospitalization or Surgery

#### 18. Before hospitalization

- 18.1. Make sure your surgeon follows the Universal Protocol (Joint Commission on Accreditation of Healthcare Organization's system for preoperative verification, operative site marking, and time-out for final verification before starting the procedure).
- 18.2. Ask if you can take your regular medications, and what to eat or drink.
- 18.3. Ask about risks and potential complications of surgery, expected outcomes, and alternatives to surgery.
- 18.4. Ask how many of these procedures are done at this hospital. Choose a hospital where the procedure or surgery is performed on many patients.
- 18.5. Ask how many of these procedures the surgeon has done.
- 18.6. Ask if your surgeon is board certified.
- 18.7. Make sure you understand why you are having the surgery.
- 18.8. Visit the hospital's Web site to learn what you need to know before you are admitted.
- 18.9. Ask the surgeon to explain exactly what will be done and what to expect after the surgery.
- 18.10. Know your course of treatment so you will notice if anything isn't right.
- 18.11. Ask what to expect during the recovery period.
- 18.12. Ask who will manage your care while you are in the hospital.
- 18.13. Make sure every professional involved in your care has your health information.
- 18.14. Make sure all professionals treating you agree on what will be done.
- 18.15. Keep records from previous hospitalizations; share them with your health care team.
- 18.16. Verify the information on your identification bracelet.
- 18.17. Read all forms thoroughly before signing. Make sure all information is correct, e.g., site of surgery.

#### 19. Medication

- 19.1. Send your usual medications home with your family.
- 19.2. Ask your doctor to tell you the names and reasons for drugs you will have while hospitalized.
- 19.3. Ask for a copy of your hospital medication administration record. Check it for accuracy.
- 19.4. Look at all medications before you take them, ask questions if it doesn't look right.
- 19.5. Ask your nurse to name any medication before you take it, to make sure it is the correct drug.
- 19.6. If a medication has not been given at the expected time, notify a nurse.
- 19.7. Read the contents of the intravenous bag.
- 19.8. Ask how long intravenous administration should take. Observe to see if it is running too fast or slow.
- 19.9. Tell your nurse or doctor if you don't feel well after receiving medication, or if you think you are having side effects.
- 19.10. Review your medications with doctor, nurse, or pharmacist before you go home. Change medication list accordingly.

#### 20. Precautions

- 20.1. Make sure care providers verify your identity before any procedure or medication.
- 20.2. Remind care providers of allergies before any procedure.
- 20.3. Before any test or procedure, ask if any dyes or medicines will be used.
- 20.4. Make sure the correct site is marked.
- 20.5. Make sure you are familiar with the operation of any equipment used in your care.
- 20.6. Be aware of the danger of falls after surgery. Ask for help, especially at night.
- 20.7. Let your nurse know if you notice any problems with dressings or catheters.
- 20.8. Ask friends and relatives not to visit if they feel ill.

#### 21. Instructions

- 21.1. Follow instructions about breathing treatments and getting out of bed.
- 21.2. Get post-op instructions about resuming activities, problems to watch for.